

# **Alzheimer's Association**

## **STATEMENT OF**

**Linda Sabo, MS  
on behalf of the**

**ALZHEIMER'S ASSOCIATION**

**presented to**

**Committee on Veterans Affairs  
United States House of Representatives  
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Mr. Chairman and members of the committee, thank you for giving me the opportunity to testify at this important hearing. I am Linda Sabo, executive director of the Western New York Chapter of the Alzheimer's Association. The chapter serves Buffalo and eight surrounding counties in the western part of New York State.

Since 1997, my chapter and three other Alzheimer's Association chapters in upstate New York have been working with VA staff from the Veterans Integrated Services Network (VISN) 2 to create a coordinated system of care for veterans with Alzheimer's disease and other dementias. This initiative, called Partners in Dementia Care, is important for two reasons.

One, there is a large number of veterans suffering from Alzheimer's disease and other dementias. A recently completed study using VA data shows that 7.3% of veterans age 65 and over who received VA services between 1997 and 2001 had a documented diagnosis of Alzheimer's disease or another dementia.<sup>1</sup> Our experience in Partners in Dementia Care indicates that many veterans with these conditions have not received a diagnosis. Thus, the true prevalence of Alzheimer's disease and other dementias in veterans who use VA services is undoubtedly much higher. Moreover, VA data show that, on average, these veterans use substantial amounts of VA services, including hospital, urgent care, primary care, and institutional and non-institutional long-term care.

Many veterans who are not currently using VA services also have Alzheimer's disease and other dementias. Recent data for the U. S. population as a whole indicate that in 2000, 13% of people age 65 and over had Alzheimer's disease, with the proportion increasing from 2% of those age 65-74 to 42% of those age 85+,<sup>2</sup> and these figures do not include people with other dementias. Thus, the number of veterans with Alzheimer's disease and other dementias who are not now using VA services is undoubtedly also large. Given the predicted 3-fold increase by 2010 in the number of veterans age 85+, the total number of veterans with Alzheimer's disease and other dementias can be expected to increase rapidly, both among current users and non-users of VA services. We must be prepared to meet the needs of these veterans.

A second reason the Partners in Dementia Care initiative is important is that the VA must find innovative ways to ensure appropriate services and support are provided to veterans with Alzheimer's disease and other dementias. This initiative provides a best practice model for ensuring such services and support.

The Partners in Dementia Care initiative is groundbreaking because of the extent of ongoing cooperation and joint activity between the VA and Alzheimer's Association chapters. The working partnership we have developed goes far beyond the usual referrals that Alzheimer's Association chapters might make to a VA medical center or, conversely, that VA staff might make to an Alzheimer's Association chapter. VA physicians, nurses, and other VISN 2 staff worked with our chapters to plan the Partners in Dementia Care initiative. We identified the

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<sup>1</sup> Kunik ME, Krishnan LL, Petersen NJ, et al., Prevalence of Dementia Among VA Medical Care System Users, poster presentation to the VA QUERI conference, "Enhancing Impact Through Integration and Collaboration," Alexandria, VA, Dec. 10-12, 2003.

<sup>2</sup> Hebert LE, Scherr PA, Bienias JL, et al., "Alzheimer disease in the US population: prevalence estimates using the 2000 Census," Archives of Neurology, 60:1119-1122, 2003.

health care, long-term care, and supportive services that each of our organizations can provide for veterans with Alzheimer's disease and other dementias and their families, and we participated in joint training for staff of both of our organizations.

Coordination of care has been a problem, both within the VA and between the VA and community agencies. Even if needed services are available, including the important non-institutional services mandated by the Millenium Act, veterans with Alzheimer's disease and other dementias may not know about or receive the services. The Partners in Dementia Care initiative is intended to make sure that these veterans and their families are connected to VA and non-VA services that can help them.

Our previous experience has been that families who receive a referral to the Alzheimer's Association from the VA or any other health care system usually wait an average of more than 2 years before contacting us. By that time, their problems have reached a crisis point. Moreover, many families never contact us. In Partners in Dementia Care, we developed an effective way of addressing this issue. With informed consent from the veteran (if capable) and the veteran's family, contact information for the family was provided to the chapter. As a result, the chapter was able to call the family to offer information and supportive services, instead of waiting for the family to contact the chapter.

The four Alzheimer's Association chapters that are participating in the Partners in Dementia Care initiative value the Partners in Dementia Care initiative because it helps us ensure that veterans and their families who contact us are quickly and effectively connected to the VA for health care and long-term care services they are eligible for, while also having access to the information, education and training programs, support groups, and other services provided by the Alzheimer's Association. For the VA, the initiative creates a way to improve the care available to veterans and ensure that VA and non-VA community services are coordinated.

Results of the Partners in Dementia Care initiative show that this best practice model of care can increase early identification and diagnosis of Alzheimer's disease and other dementias and improve quality of care, access to needed information and services, and satisfaction for veterans with these conditions and their families.

- More than 500 veterans with Alzheimer's disease and other dementias were enrolled in Partners in Dementia Care. Many of these veterans had not been previously identified or diagnosed. Although most of the enrollees were not capable of participating in evaluation interviews, 85 veterans were capable of responding. On average, these veterans reported receiving the information and support they needed, including information about available treatments and support in obtaining needed help. They also reported high satisfaction with the VA and non-VA services they received.
- Almost all of the veterans enrolled in Partners in Dementia Care had a family caregiver, and 270 of these family caregivers participated in interviews about the initiative. They reported receiving extensive information and support, especially information about how to manage daily care for the veteran and help with accessing needed VA and non-VA services.

- VISN 2 was the only VA site among the six health care systems that participated in a larger national demonstration of coordinated Alzheimer's and dementia care. Among these sites, reported satisfaction with care was higher for family caregivers of the enrolled veterans in the VISN 2 site than for family caregivers of enrollees in any of the other five, non-VA sites.
- VA physicians, nurses, and other VA and chapter staff who responded to interviews about the Partners in Dementia Care initiative (n = 209) had strongly positive attitudes about its impact on quality of care and outcomes for veterans. More than 80% of these care providers said, for example, that the initiative improved their own ability to care for their patients with dementia, increased their confidence that the and services needed by these patients and their families were available, and improved ongoing care management for the veterans and their families.

We do not have comparable information for veterans with Alzheimer's disease and other dementias who did not participate in the Partners in Dementia Care initiative in VISN 2 or veterans, families, and care providers in other VISNs. Interestingly, a GAO study of Millenium Act services provided for veterans in all VISNs in 2001 found that VISN 2 provided non-institutional Alzheimer's care for three times more veterans than the average for all other VISNs (689 vs. 191 veterans receiving services on the day of the survey).<sup>3</sup> VISN 2 also provided non-institutional adult day services for almost three times more veterans than the average for all other VISNs (349 vs. 133 veterans receiving adult day services on the day of the survey).<sup>3</sup>

The Alzheimer's Association, VA staff from VISN 2 and VA headquarters, and other VA and non-VA researchers are currently working together on proposals to implement and evaluate the Partners in Dementia Care best practice model in other VISNs. We are aware that all the non-institutional services mandated by the Millenium Act are not uniformly available to all veterans. We encourage the VA to increase the availability of these services. We do not believe, however, that the VA can provide all the services needed by veterans with Alzheimer's disease and other dementias. The services provided by Alzheimer's Association chapters are also needed. Chapter services are especially important in helping families cope with caregiving tasks and maintain their relative with dementia at home for as long as possible.

Although this hearing is focused on non-institutional services we also want to stress the need for adequate nursing home beds for veterans with Alzheimer's disease and other dementias who need nursing home care and have no family at all or no family that is able to provide this level of care.

We hope and expect to continue working with the VA to increase the availability of high-quality institutional and non-institutional care and the coordination of VA and non-VA services in order to improve outcomes for veterans with Alzheimer's disease and other dementias.

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<sup>3</sup> General Accounting Office, testimony submitted to the U.S. Senate Committee on Veterans' Affairs, Washington DC, April 25, 2003, pps. 17-33.